

# Create-a-Medical-Chart: Duchenne Muscular Dystrophy

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*Disclaimer: The findings and conclusions in this report are those of the author(s) and do not necessarily represent the views of the Centers for Disease Control and Prevention.*

## **Create-a-Medical Chart: Duchenne Muscular Dystrophy**

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### **Summary**

Students will play the role of medical residents and collaborate to create a medical chart for a patient with Duchenne muscular dystrophy (DMD). Each group will perform guided Internet research to learn about DMD and participate in a simulated case study review session.

### **Learning Outcomes**

- Students will assemble a medical chart for a fictional patient.
- Students will be able to recognize signs and symptoms of DMD, explain the diagnosis and suggest treatments, and develop a prognosis for a patient with DMD.

### **Materials**

1. Computers with Internet access
2. Print resources
3. Manila folders

### **Total Duration**

3–4 hours

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## **Procedures**

### **Teacher Preparation**

Prepare manila folders for each group in which to house the medical chart files as described in Step 3. Manila folders with expandable bottoms would work well if available. Include in the folder the “SOAP Notes Form,” and the “SOAP Notes Tip Sheet.” All other forms required in the medical chart file should be generated by the students.

For content background, you’ll want to become familiar with information about DMD. Review the website “A Teacher’s Guide to Duchenne Muscular Dystrophy” listed in the Web resources section below.

It is important to treat the topic of this lesson plan in a sensitive manner. Students might have or know someone who has a genetic condition. Adapt the lesson plan as necessary to fit individual student needs.

The “Create-a-Medical Chart Scoring Rubric” found in the conclusion should be introduced to students before beginning the project.

The case study review session in the conclusion should be set up as close to a roundtable discussion environment as possible. In this lesson plan, you will lead the case study review session. However, if a more rigorous lesson plan is desired, students may conduct the case study review session without your input.

**Web Resource**

Title: A Teacher's Guide to Neuromuscular Diseases

URL: <http://www.mdausa.org/publications/tchrdmd/>

Description: There are many things that people with muscle diseases, their caregivers, their teachers, and their friends can do to make living with a disability easier. This website gives information about neuromuscular diseases, including DMD, and lists some steps that can be taken to accommodate a student with DMD.

**Supplemental Document**

Title: Notes About Student Expectations and Evaluation for Beginning Teachers

Filename: Medical Chart Teacher Notes.doc

Description: Additional notes about the expectations and evaluation of the medical chart are included in this document.

**Step 1****Duration: 30 minutes**

Inform students that they are going to play the role of medical residents. For this lesson plan, students will become experts on Duchenne muscular dystrophy. Their training will culminate in creating a medical chart for a child who may have DMD. To begin their training, divide the class into three groups that correspond to three stages of DMD (early stage, middle stage, and late stage). Have each group review the corresponding Web resource below and develop a summary of their assigned DMD stage.

**Web Resources**

Title: Muscular Dystrophy Campaign: Early stage

URL: [http://www.muscular-dystrophy.org/care\\_support/personal\\_care\\_and\\_support/occupational\\_therapy/the\\_early\\_stage.html](http://www.muscular-dystrophy.org/care_support/personal_care_and_support/occupational_therapy/the_early_stage.html)

Description: The early stage covers diagnosis to difficulty in climbing stairs. This website offers information about the manifestations of the disease in the early stage and what can be done to make the environment of a child with DMD more accommodating. This website is sponsored by the Muscular Dystrophy Campaign, a United Kingdom charity focusing on all muscular dystrophies.

Title: Muscular Dystrophy Campaign: Middle stage

URL: [http://www.muscular-dystrophy.org/care\\_support/personal\\_care\\_and\\_support/occupational\\_therapy/the\\_middle\\_stage.html](http://www.muscular-dystrophy.org/care_support/personal_care_and_support/occupational_therapy/the_middle_stage.html)

Description: The middle stage covers difficulty in walking to the use of powered wheelchair out of doors. This website offers information about the manifestations of the disease in the middle phase and what can be done to make the environment of a child with DMD more accommodating of his needs. This website is sponsored by the Muscular Dystrophy Campaign, a United Kingdom charity focusing on all muscular dystrophies.

Title: Muscular Dystrophy Campaign: Late stage

URL: [http://www.muscular-dystrophy.org/care\\_support/personal\\_care\\_and\\_support/occupational\\_therapy/the\\_late\\_stage.html](http://www.muscular-dystrophy.org/care_support/personal_care_and_support/occupational_therapy/the_late_stage.html)

Description: The late stage covers use of an indoor/outdoor powered wheelchair to terminal stage. This website offers information about the manifestations of the disease in the late phase and what can be done to make the environment of a child with DMD more accommodating. This website is sponsored by the Muscular Dystrophy Campaign, a United Kingdom charity focusing on all muscular dystrophies.

## **Step 2**

**Duration: 30 minutes**

To continue their training, have students create an information sheet for the parents of children with DMD. The explanations about the disease should be in terms the parents can understand. It is important for students to be sensitive to the parent's feelings when wording the information sheet. Students should use the websites that follow when gathering information.

### **Web Resources**

Title: Your Genes, Your Health: Duchenne/Becker Muscular Dystrophy

URL: <http://www.ygyh.org/dmd/whatisit.htm>

Description: This site covers inheritance, symptoms, incidence, treatment, cause, testing, and screening.

Title: Muscular Dystrophy Association: Facts about Duchenne and Becker Muscular Dystrophies

URL: <http://www.mdausa.org/publications/fa-dmdbContext.html>

Description: This website, sponsored by the Muscular Dystrophy Association, has information about the disease condition, inheritance, treatment, affects on the body, and the search for a treatment and cure.

Title: Parent Project Muscular Dystrophy

URL: <http://www.parentprojectmd.org/>

Description: This is the home site for Parent Project Muscular Dystrophy, an organization that leads the muscular dystrophy community. The website includes information about understanding DMD, research, treatment and care, educational issues, emotional issues, legislative action, and resources.

## **Step 3**

**Duration: 30 minutes**

Next, playing the role of lead physician, instruct students (who are playing the role of medical residents) to create a medical chart for a new patient. The patient is a child who has been referred to the clinic because he has been displaying some unusual symptoms, and one of his doctors suspects that the symptoms may be consistent with DMD. Discuss with students the content and use of a medical chart, or have students access the PowerPoint presentation, "Components of a Hospital Medical Chart," created by the Virginia Department of Health (see Web resources). As the students create each piece of their medical chart, they should use the Web resources in the Step 1 that correspond to their group.

The medical chart should include the following:

### **A. SOAP Notes**

SOAP is an acronym for "subjective findings, objective findings, assessment, and plan" and is a form used by doctors to assess a patient's current condition. This portion of the chart will be used to describe the clinical signs and symptoms for the

patient. Students should use what they have learned about the early stages of DMD to create a description of a child who might have DMD. Students should use the “SOAP Notes Form” found in their medical chart file for this activity. Students will find the “SOAP Notes Tip Sheet” very helpful when filling out the form.

#### **Web Resource**

Title: Components of a Hospital Medical Chart

URL:

[http://www.vdh.state.va.us/epr/pdf/MaySeminar/Components\\_Hospital\\_Medical\\_Chart.pdf](http://www.vdh.state.va.us/epr/pdf/MaySeminar/Components_Hospital_Medical_Chart.pdf)

Description: This website from the Virginia Department of Health is a PowerPoint presentation that describes the contents of a hospital medical chart. Virginia’s example is for meningitis, but the explanation of the contents can be generalized for the purposes of this lesson.

#### **Supplemental Documents**

Title: SOAP Notes Tip Sheet

File Name: SOAP Notes Tip Sheet.doc

Description: This handout gives students directions and suggestions for filling out the SOAP Notes Form.

Title: SOAP Notes Form

File Name: SOAP\_Notes\_Form.doc

Description: This form is to be used by students as a template for the SOAP notes to be included in their medical charts.

### **B. Family History**

Students should use what they have learned about DMD to create a sample family history for the patient.

### **C. Suggested Lab Tests and Results**

The typical diagnostic sequence for a person with DMD involves testing levels of creatine kinase (a kind of protein found in muscles), a muscle biopsy, and molecular DNA testing. Have students provide a brief description of these tests and indicate the expected results of the tests for a patient with DMD and a patient without DMD. If testing reveals that there are high levels of creatine kinase, this indicates that muscle damage is present, which is consistent with DMD. However, high levels of creatine kinase could result from processes other than DMD, so it is important to conduct further testing. The muscle biopsy might include information about fibrosis, fat infiltration, changes in the central nuclei, degeneration and/or regeneration of dystrophin, etc. The DNA test results could reveal the type of mutation, reveal no mutation and recommend further testing (such as sequencing), or reveal no mutation after sequencing and other standard laboratory methods and recommend a muscle biopsy to confirm diagnosis. The website “Duchenne/Becker Muscular Dystrophy” that follows would be a good place to start the work on the lab reports.

#### **Web Resource**

Title: Duchenne/Becker Muscular Dystrophy

URL: <http://www.cdc.gov/ncbddd/duchenne/causes.htm>

Description: This website sponsored by CDC's National Center on Birth Defects and Developmental Disabilities gives information about the causes of muscular dystrophy and the kinds of tests that help diagnose it.

Title: Duchenne Muscular Dystrophy: How is Duchenne/Becker diagnosed?

URL: <http://www.ygyh.org/dmd/diagnosis.htm>

Description: This web page is part of the "Your Genes, Your Health" website. The site gives information about muscular dystrophy causes and the kinds of tests that help diagnose it. The tests described include clinical features, CK (CPK) assay, DNA testing, muscle biopsy, and prenatal testing.

#### **D. Overall Summary**

The summary can look like an essay written by the attending physician in charge of the patient's case. The format varies, so students may determine their own format. The essay should summarize the information from the other three sections, including the data, diagnosis, and recommendations for further action.

#### **Conclusion**

**Duration: 45 minutes**

#### **Case Study Review Session**

Have students sit in a roundtable-type setting to report about the contents of the medical charts they created in Step 3. In the role of lead physician, conduct the review and ask each group to present their chart components. Use the "Create-a-Medical Chart Scoring Rubric" to assess the roundtable case study review session and serve as a post-assessment for the entire project.

#### **Supplemental Document**

Title: Create-a-Medical Chart Scoring Rubric

File Name: Create-a-Medical Chart\_scoring\_rubric.doc

Description: This scoring rubric aligns with the assignment parameters and clarifies expectations and grading values.

#### **Assessment**

At the end of the project, the "Create-a-Medical Chart Scoring Rubric" is used to evaluate student work on the entire project. The rubric aligns with the assignment parameters and explains expectations and grading values. The rubric can be found in the conclusion step.

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#### **Modifications**

#### **Extension**

In addition to work being done to look at muscular dystrophy in individual patients, there is work being done to look at muscular dystrophy in populations. To conclude the Create-a-Medical Chart lesson, have students investigate current population-based research being done by CDC on DMD and a milder form of the disease known as Becker muscular dystrophy. The combined spectrum of these diseases is known as Duchenne/Becker muscular dystrophy, or DBMD. Direct students to the CDC Web resource to answer questions in the "What is CDC doing for DBMD?" worksheet. An answer key, "What is CDC doing for DBMD? – Answer Sheet," is included for your

reference. Give students a chance to discuss the larger picture of DBMD research once they have completed the worksheet.

### **Web Resource**

Title: MD STARnet: What is CDC doing about DBMD?

URL: <http://www.cdc.gov/ncbddd/duchenne/cdc.htm>

Description: This website from CDC's National Center on Birth Defects and Developmental Disabilities provides information about the center's research program for DBMD. There are many different projects related to DBMD. The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet) is one project designed to identify all children with DBMD in defined geographic areas by using information in medical records from clinics and hospitals. The information will provide better estimates of the number of people with DBMD, which will in turn allow communities to identify resource needs and provide better services. Students should use this site to complete the questions in the "What is CDC doing for DBMD?" worksheet.

### **Supplemental Document**

Title: What is CDC doing for DBMD? Worksheet

File Name: What is CDC doing for DBMD.doc

Description: This worksheet provides a place for students to record information about what CDC is doing to find answers about Duchenne and Becker muscular dystrophy.

Title: What is CDC doing for DBMD? – Answer Sheet

File Name: What is CDC doing for DBMD – Answer Sheet.doc

Description: This worksheet provides possible answers for the questions in the "What is CDC doing for DBMD?" worksheet.

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## **Education Standards**

### **National Science Education Standards**

LIFE SCIENCE, CONTENT STANDARD C:

As a result of their activities in grades 9–12, all students should develop understanding of

- **The cell**
- **Molecular basis of heredity**
- Biological evolution
- Interdependence of organisms
- **Matter, energy, and organization in living systems**
- **Behavior of organisms**

SCIENCE IN PERSONAL AND SOCIAL PERSPECTIVES, CONTENT STANDARD F:

- **Personal and community health**
- Population growth
- Natural resources
- Environmental quality
- Natural and human-induced hazards
- **Science and technology in local, national, and global challenges**

**Notes About Student Expectations and Evaluation for Teachers**  
**DMD Medical Chart Lesson**

Create-a-Medical Chart: Duchenne Muscular Dystrophy  
Gail Wortmann, CDC's 2005 Science Ambassador Program

**Expectations**

Even though students will be learning about medical charts in this lesson, the construction of the chart is not the main purpose of this assignment. The main objective of this lesson is to learn about a disease condition, both in its small details and in the big picture. The disease condition under investigation is Duchenne muscular dystrophy; students will study inheritance patterns, symptoms, treatment, and prognosis over time. Keep the main goal in mind; don't focus too much on the formats of the various content pieces (SOAP Notes, lab reports, etc.).

Before beginning medical chart work, as a group, the class should decide on a patient name and the names of close family members. Make sure the patient is a boy and there are siblings of both genders to make the inheritance pattern study more interesting.

**Parent Information Sheet**

The information sheet for the parents should contain details about DMD one might find in a standard science report. Depending on the dynamics of the student groups, this information sheet can be limited to one page, or it can be a bigger assignment if more work is needed to balance work among group members. Students should write the report in their own words, making sure the language could be understood by the average person. Students should aim for a reading level of eighth grade or lower. The reading level can be checked using Microsoft Word's spellcheck. Use the Help function to see how to turn on the readability statistics option. Using shorter sentences and words with fewer syllables will lower the reading level.

**SOAP Notes**

Students will fill in the SOAP Notes by following the form and tip sheet given. There are many websites and references available on Duchenne muscular dystrophy. Be sure to check your school and local library for information in addition to resources on the Web. Usually a child with DMD and his family will be referred to a genetic counselor, a physical therapist, and other specialists including a counselor or psychologist in the process of diagnosis and treatment.

**Overall Summary**

An overall summary is included in this assignment to ensure that students talk about their results with each other. The summary should include general statements from each group member about the information they found and how it influences the bigger picture for the patient and his family.

**Grading**

In grading the medical chart, points can be awarded for completion and accuracy of information. The assignment could be graded using a "time-it-takes" formula. In the formula, each day is worth about 20 points. If an assignment takes 5 days, it is worth 100 points. Additional points could be added if extra thought or creativity is required and the students do a good job. This concept can be adjusted to your own grading scale.



You can choose to give the entire group a grade, each individual a grade for his or her part in the medical chart, or a combination of both. To foster better cooperation, giving individual grades for different pieces of the work and a group grade for the overall summary and roundtable discussion is suggested.

## **SOAP Notes Tip Sheet**

Create-a-Medical Chart: Duchenne Muscular Dystrophy  
Gail B. Wortmann, CDC's 2005 Science Ambassador Program

In the role of medical residents, students need to use the tools of the medical trade. When working with patients, students will use the patient progress note format known as SOAP. SOAP is an acronym that stands for "subjective data, objective data, assessment, and plan." The SOAP format gives structure to gathering information about the patient, diagnosing the problem, and setting up a plan for treatment. The key to writing a good SOAP is brevity. A medical resident needs to convey the information in a concise manner.

### **Directions**

Tips for writing good SOAP notes from the Virtual Naval Hospital are provided below. The Virtual Naval Hospital personnel wrote these guidelines as a result of "Desert Storm" when they were working to improve patient care by improving the information gathered from and about patients.

In addition to the SOAP notes, make sure you include the patient's medical history. The information in a medical history is based on what happens before the current condition that brought the patient to your care.

### **Tips on Medical SOAP Notes (1)**

Heading: The heading of the progress note should include the date, time, and who is writing the note. Always write current medications and doses the patient (pt) is taking, if known, at the top.

Subjective Data: Subjective information is what the patient tells you. How are they feeling? What are their symptoms? What are they eating? Are they sleeping well? Are they moving on their own, urinating, defecating, passing gas? If they have diarrhea, describe it here (e.g., "green and watery x3 last night").

Clarify any chief complaint. If a patient tells you he is "doing poorly," do not write this in your note. Instead, get a good description of the symptoms. For example, "Pt. c/o (Patient complains of) abdominal bloating and pain in right shoulder made worse by breathing and exertion."

Objective Data: Objective information is what you gather from your physical exam and from other tests. Begin with the vital signs. You should also record the patient's weight if daily weights are being recorded. Then write about your physical exam including only pertinent positives and negatives.

After the exam, write the results of laboratory tests that have not yet been entered into the chart. After the labs, include the results of other studies that have not yet been noted in the chart. These include EKG, x-rays, CT scans, etc. If a lab or test has been ordered but the results are not yet back, note that the test is pending.

Assessment: The assessment is what you think is wrong with the patient. The assessment is also a summary of how the patient is doing and what has changed from

the previous day. For example, has his fever gone down, does he still have symptoms, has his white count improved?

Plan: The plan is what you are going to do about the problem, such as prescribe medication, order labs or tests, or call for consults.

### SOAP Notes Example (1)

An example SOAP might look something like this:

<b>EMERGENCY CARE &amp; TREATMENT</b> (Medical Record)				<i>Lakeside Clinic</i>	
Arrival				Transportation to hospital <input checked="" type="checkbox"/> Private vehicle <input type="checkbox"/> Other <input type="checkbox"/> Ambulance	History obtained from: <input checked="" type="checkbox"/> Patient <input type="checkbox"/> Other:
Date			Time:		Allergies:
Day <b>12</b>	Month <b>1</b>	Year <b>04</b>	<b>1:15 pm</b>		<b>none</b>
Patient: <b>Carol Wigland</b>					Phone: <b>640-223-1234</b>
Chief Complaints: <b>Extreme shoulder pain</b>				Sex <b>F</b>	Age <b>51</b>
Medications: <b>vitamins, calcium</b>					
<p><b>SOAP Note Description:</b> (1) Subjective data (Pertinent History); (2) Objective data (Examination – include results of tests and X-rays); (3) Assessment (Diagnosis); (4) Plan (Treatment/Procedures—include medications given and follow-up)</p> <p><b>S: Subjective Data:</b>  Patient c/o (complains of) pain in left shoulder, especially when reaching backwards or straight overhead. Pt denies restriction of motion except by pain. Pain started when doing upper body lifting with light weights. Pt has trouble sleeping due to pain. Pt takes ibuprofen when needed.</p> <p><b>O: Objective Data (Test Results):</b>  Vitals: BP = 106/64 Weight = 130 lbs. Bony palpation of shoulder indicates pain in the area of the bursa. Apley Scratch test indicates limited ROM (range of motion). Strength test (resistance) shows reduced strength in left arm. Movement of arm shows signs of pain only in specific directions.</p> <p><b>A: Assessment (Diagnosis):</b>  51 y/o female who presents with bursitis in the left shoulder from repetitive motion.</p> <p><b>P: Plan (Procedures/Treatment):</b>  Cortizone injection into shoulder joint cavity. When pain subsides, start exercises for circumduction and abduction of the shoulder. Re-evaluate in 2 weeks.</p>					
SIGNATURE OF PROVIDER:					
SUMMARY and INSTRUCTIONS FOR PATIENT:					

### References

Virtual Naval Hospital. SOAP Notes [online]. 1997–2005. [cited 2005 Jun 23]. Available at URL: <http://www.vnh.org/SickcallScreeners/SOAPNotes.html>.

### SOAP Notes Form

Create-a-Medical Chart: Duchenne Muscular Dystrophy  
Gail B. Wortmann, CDC's 2005 Science Ambassador Program

MEDICAL CARE & TREATMENT (Medical Record)				Local Clinic		
Arrival				Transportation to hospital <input type="checkbox"/> Private vehicle <input type="checkbox"/> Other <input type="checkbox"/> Ambulance	History obtained from: <input type="checkbox"/> Patient <input type="checkbox"/> Other:	
Date			Time:		Allergies:	
Day	Month	Year				
Patient:				Telephone:		
Chief Complaints:				Sex	Age	Medications:
<p><b>SOAP Note Description:</b> (1) <i>Subjective data (Pertinent History)</i>; (2) <i>Objective data (Examination - include results of tests and X-rays)</i>; (3) <i>Assessment (Diagnosis)</i>; (4) <i>Plan (Treatment/Procedures—include medications given and follow-up)</i></p> <p><b>S: Subjective Data:</b></p>          <p><b>O: Objective Data (Test Results):</b></p>          <p><b>A: Assessment (Diagnosis):</b></p>          <p><b>P: Plan (Procedures/Treatment):</b></p>          						
SIGNATURE OF PROVIDER:						
SUMMARY and INSTRUCTIONS FOR PATIENT:						

## Create-a-Medical Chart Scoring Rubric

Create-a-Medical Chart: Duchenne Muscular Dystrophy  
Gail B. Wortmann, CDC's 2005 Science Ambassador Program

Name\_\_\_\_\_

Create-a-Medical Chart Scoring Rubric				
Criteria	Pts	Full credit	75% credit	Not Yet (resubmit)
<b>Parent Information Sheet:</b> Description of DMD Understandable language Sensitive wording	20	Thorough disease description; language is understandable by parent; sensitive wording used	Disease description present; language acceptable	Disease description lacking; language inappropriate
<b>SOAP Notes:</b> Subjective data Objective data Assessment Plan	20	SOAP notes reflect DMD and are realistic; all components are present	Notes reflect DMD; one component is missing	Notes are scarce; components are missing and details are unrealistic
<b>Family History:</b>	10	Great detail given; quality of information high; realistic entries	Details given; information accurate; realistic entries	Few details evident; information questionable; unrealistic entries
<b>Lab Results:</b> Creatine kinase Muscle biopsy Functional tests	10	Copies of all lab reports are included in the medical file with good detail	Copies of some lab reports are included in the medical file with sufficient detail	Copies of lab reports are missing from the medical file

<b>Overall Summary:</b>	10	Relevant concluding comments from the physician to the patient are included	Comments from the physician to the patient are present	Comments from the physician to the patient are not present
<b>GUM:</b> Grammar, Usage, Mechanics	5	No errors in grammar, usage, or mechanics	Few errors in grammar, usage, or mechanics	Many errors in grammar, usage, or mechanics
<b>Sources:</b> Noted	5	Website URLs appear next to information/image or are listed at bottom with reference #'s; paper resource information is present	Some URLs appear next to information/image or are listed at bottom; some of the paper resources are cited	Sources not indicated
<b>Case Study Review Session:</b>	20	Student is organized and cooperates with others to describe case and formulate recommendations	Student is organized but may have difficulty working with others	Student is disorganized and does not collaborate with others
<b>Total Points</b>	100			
<b>Grade</b>				

## **What is CDC doing for DBMD?**

Create-a-Medical Chart: Duchenne Muscular Dystrophy  
Gail B. Wortmann, CDC's 2005 Science Ambassador Program

The Centers for Disease Control and Prevention (CDC) is working to learn more about Duchenne and Becker muscular dystrophy (DBMD) in populations.

Answer the following questions about CDC's DBMD activities.

1. To provide families affected by DBMD with better services, CDC is working to provide better information about DBMD to public health departments and health care providers. What are the six questions CDC is researching to help meet this goal?
2. Describe the Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet). What is its goal? How is information for the surveillance and research collected? What type of information is collected?
3. Who does CDC work with to gather information on DBMD?
4. What types of information does CDC hope to gain from families to clarify the DBMD picture?
5. DBMD is typically found in boys. Do girls ever have any symptoms? If so, what girls are affected and how are they affected?

## **What is CDC doing for DBMD? – Answer Sheet**

Create-a-Medical Chart: Duchenne Muscular Dystrophy  
Gail B. Wortmann, CDC's 2005 Science Ambassador Program

The Centers for Disease Control and Prevention (CDC) is working to learn more about Duchenne and Becker muscular dystrophy (DBMD) in populations.

Answer the following questions about CDC's DBMD activities.

1. To provide families affected by DBMD with better services, CDC is working to provide better information about DBMD to public health departments and health care providers. What are the six questions CDC is researching to help meet this goal?
  - **How common is DBMD?**
  - **Is it equally common in different racial and ethnic groups?**
  - **What are the early signs and symptoms of DBMD?**
  - **Do factors such as the type of care received or the type of gene changes affect the severity or course of DBMD?**
  - **What medical and social services are families receiving?**
  - **Do different populations receive different care?**
2. Describe the Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet). What is its goal? How is information for the surveillance and research collected? What type of information is collected?

**CDC's MD STARnet is a surveillance system for DBMD. Its goal is "to identify all patients with DBMD in specific geographic areas by using information from different sources, such as clinic medical records and hospital records." In addition to noting cases, researchers gather information about treatments and overall well-being from clinical records. Families affected by DBMD are invited to speak with public health representatives to provide information related to DBMD not found in medical records.**

**Researchers work closely with Muscular Dystrophy Association clinics, neuromuscular clinics, emergency rooms, pathology laboratories, orthopedists, and other muscular dystrophy associations to gather information about people affected with muscular dystrophy. By using so many sources, they minimize the number of missed cases.**

**MD STARnet collects basic demographic, treatment, and medical information as well as information on the types of clinics in which care was received.**

3. Who does CDC work with to gather information on DBMD?

**CDC works with state public health departments and universities on its DBMD research. Researchers work with hospitals, clinics (Muscular Dystrophy**



**Association clinics and others), and families to gather the information they need.**

4. What types of information does CDC hope to gain from families to clarify the DBMD picture?

**Families will be asked about what services they need, what access they have to services, and what barriers stand in the way of receiving those services. Families will be asked about their opinions concerning newborn screening for DBMD, especially those who found out about DBMD through newborn screening projects. Researchers will ask about adaptations families have made for their member with DBMD.**

5. DBMD is typically found in boys. Do girls ever have any symptoms? If so, what girls are affected and how are they affected?

**Some females who are DBMD carriers have clinical symptoms. Heart problems later in life are sometimes seen and are characterized by shortness of breath and the inability to do even moderate exercise. Medications might be successful in treating these patients. Research will help CDC determine ways to promote preventative cardiac care messages in this population.**